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# The impact of COVID-19 measures on children with disabilities and their families in Uganda

Femke Bannink Mbazzi<sup>a,b,c</sup> , Ruth Nalugya<sup>b</sup>, Elizabeth Kawesa<sup>b</sup>,  
Claire Nimusiima<sup>b</sup>, Rachel King<sup>d</sup>, Geert van Hove<sup>a</sup> and  
Janet Seeley<sup>b,c</sup> 

<sup>a</sup>Faculty of Psychology and Educational Sciences, Ghent University, Ghent, Belgium; <sup>b</sup>Social Aspects of Health, MRC/UVRI & LSHTM Uganda Research Unit, Entebbe, Uganda; <sup>c</sup>Department of Global Health and Development, London School of Hygiene and Tropical Medicine, United Kingdom; <sup>d</sup>Institute for Global Health Sciences, University of California, San Francisco, USA

## ABSTRACT

To understand the impact of the COVID-19 public health response on families of children with disabilities in Central Uganda we conducted phone interviews with parents and children during the first 5 months of the outbreak (March - July 2020). Most parents and children were well informed about COVID-19 and were keen to adhere to government prevention measures. The majority said lock-down measures had a negative effect on their mental and physical health, social life, finances, education and food security. Access to medical services and medication for chronic illness had been limited or absent due to restrictions in travel, some facilities restricting access, and limited financial resources. The majority of parents reported loss of work which resulted in difficulties in finding enough food and paying rent. Parents worried about children missing education and friends. We suggest greater attention to children with disabilities and their families when implementing mitigating and long-term responses.

## ARTICLE HISTORY



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## KEYWORDS

Disability; COVID-19;  
families; children;  
Africa; Uganda

## Points of interest

- This paper reports a study with families of children with disabilities in Uganda during the Coronavirus pandemic in 2020, known as COVID-19.
- Families of children with disabilities in Uganda are well informed about COVID-19 and try to follow prevention measures.

**CONTACT** Femke Bannink Mbazzi  [femke.bannink@mrcuganda.org](mailto:femke.bannink@mrcuganda.org); [femke.bannink@ugent.be](mailto:femke.bannink@ugent.be)  Ghent University & MRC/UVRI & LSHTM Uganda Research Unit, Entebbe, Uganda

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- Families of children with disabilities have difficulties meeting daily basic needs as they were unable to work and had no income during the COVID-19 related lock down.
- The COVID-19 response affects access to health and rehabilitation services for children with disabilities in Uganda.
- Parents of children with disabilities struggle with home education and learning due to lack of access to accessible learning materials and learning support in Uganda.
- The COVID-19 response affects the peer support networks and social support for parents of children with disabilities in Uganda.
- Children with disabilities and their families should be involved and considered in the development and implementation of the COVID-19 response.

## **Introduction**

### ***COVID-19 in Uganda***

In December 2019, a novel strain of corona virus, Severe Acute Respiratory Syndrome Corona Virus 2 (SARS-CoV2 or COVID-19), was identified in Wuhan, China, and continued to spread globally (Shereen et al. [2020](#)). In March 2020, the World Health Organisation (WHO) declared the COVID-19 outbreak to be a global pandemic (World Health Organization [2020a](#)).

Uganda confirmed its first case of COVID-19 and started implementing a response to curb the spread in March 2020. In July, at the time of writing of this paper, the country had registered over 1,100 COVID-19 cases and 2 deaths out of more than 260,000 persons tested (Government of Uganda [2020](#)). The initial measures which were implemented from end of March until early June 2020 included regular hand-washing, social distancing, school, religious institutions, office and shop closure (only essential services continued), a ban on all private and public transport, and night curfew from 07.00 pm till 06.30am. In June 2020 private and public transport resumed, and most offices and iface masks, practised social distancing and had access to hand washing facilities. The curfew starting time was changed to 09.00 pm. Schools, sport facilities, arcades, and places of entertainment remained closed (Government of Uganda [2020](#)).

### ***The impact of COVID-19 in Sub-Saharan Africa***

During the first months of the pandemic, the possible dynamics of transmission in sub-Saharan Africa were examined through mathematical models in the absence of country wide testing data (Diop et al. [2020](#); Gilbert et al. [2020](#);

Miyachi, Tanimoto, and Kami 2020; Zhao et al. 2020). As the virus spread (World Health Organization 2020b), African governments prepared health facilities (Ademuyiwa et al. 2020; Kapata et al. 2020; Senghore et al. 2020) and developed guidelines for rehabilitation of COVID-19 patients (Ekwueme et al. 2020). Lessons learned from the HIV pandemic to combat the spread and mitigate the response were shared (Hargreaves et al. 2020). Concerns were raised regarding availability of oxygen supply (Fenton 2020; Stein et al. 2020), critical care beds and well-trained staff (Ohia, Bakarey, and Ahmad 2020; Sonenthal et al. 2020) as well as laboratory testing capacity in the region, which were lacking pre-pandemic (Oladimeji, Atiba, and Adeyinka 2020). Barriers to the public's adherence to COVID-19 prevention measures were cited in some African countries, including religious and cultural beliefs and practices in Sudan (Hezima et al. 2020) and South Africa (Jaja, Anyanwu, and Jaja 2020), poor health-seeking behaviour in Ethiopia (Shigute et al. 2020), and general distrust of the government in the Democratic Republic of Congo (Whembolua and Tshiswaka 2020). In Zimbabwe, health workers mentioned implementing the measures is hard without access to water, long-term food supplies, and daily income (Mackworth-Young et al., 2020). The overwhelming and devastating economic effect that public health measures such as curfews, bans on transport and lock-downs have on populations that are largely dependent on the informal economic sector were highlighted in Zimbabwe (Dzobo, Chitungo, and Dzinamarira 2020) and Ethiopia (Shigute et al. 2020).

### ***COVID-19 and disability***

Globally, vulnerable populations, including persons with disabilities, are often marginalised, economically disempowered, experience poor social conditions, lack access to health care, education, and social services. Understanding the effects of the COVID-19 outbreak on members of vulnerable populations, with a view to tailoring interventions, is important. The Global Rehabilitation Alliance argued in a statement made in March 2020 that there is need for scientific research to understand the consequences of COVID-19, and develop specific accessible rehabilitation programs for persons with disabilities who have had COVID-19 in low income countries.

In May 2020 the World Health Organization (WHO) released a policy brief to ensure disability inclusion in the COVID-19 response and recovery. The brief describes four areas of action: 1) mainstreaming of disability, 2) ensuring accessibility of information, facilities, services and programmes; 3) ensuring meaningful consultation with and active participation of persons with disabilities, and 4) establishing accountability mechanisms to ensure disability inclusion in all stages of the response and recovery process (United Nations 2020).

In June 2020 the Stakeholder Group of Persons with Disabilities published a report on additional and new pandemic-related barriers that persons with

disabilities encounter. They conducted semi-structured interviews and focus group discussions with 109 persons with disabilities from 54 countries worldwide (21.7% of the participants came from African countries). Findings showed that persons with disabilities had difficulties in accessing COVID-19 related information, experienced barriers in receiving social protection measures and employment, and noticed lack of disability inclusion in COVID-19 response efforts in their countries (Stakeholder Group of Persons with Disabilities for Sustainable Development 2020).

### ***Children with disabilities in Uganda***

In Uganda, a low income country in East Africa, approximately 2.5 million persons have a disability (Uganda Bureau of Statistics 2016; UNICEF 2014). In low income countries, children growing up in impoverished environments are exposed to various public health hazards, such as poor sanitation, poor nutrition, diseases and poor health services (Babb et al. 2018; Boydell et al. 2017; Dib et al. 2015; Esipisu 2019; Kimani-Murage and Ngindu 2007). Disability, malnutrition, and poverty are closely related to each other (Hume-Nixon and Kuper 2018; Mitra, Posarac, and Vick 2013). Families of children with disabilities often live on low wages, and daily earnings (Filmer 2008; Loeb et al. 2008; Lwanga-Ntale 2003). With the COVID-19 measures in place businesses have been affected and small business are struggling to survive. Although no data are available yet on the situation in Uganda, it is expected that households with children with disabilities, who were already struggling to feed themselves, will face even more difficulty now that their daily earnings have reduced.

Depending on the type of disability, children with disabilities may require more regular health care interventions, and rehabilitation services compared to typically developing children (World Health Organization 2011). Due to the COVID 19 'lock-down' measures, limited public transport availability, and reduced income of caregivers, access to health and rehabilitation facilities is likely to be affected. Between March and July 2020 national newspapers reported persons with disabilities in Uganda were facing challenges with accessing COVID-19 related information, as well as health care (Oluka 2020; Tenywa 2020).

In Uganda, and many other low income countries, children with disabilities are less likely to go to school than typically developing children and are unlikely to receive quality inclusive education (UNICEF 2014). In March 2020 schools were closed as part of the COVID-19 response, and all children, including children with disabilities who were attending school, had to start learning from home. The daily newspaper reported children with disabilities lacked support to benefit from home learning (Nantambi 2020; Salmon 2020).

## ***The Ubuntu bulamu intervention***

The *Ubuntu bulamu* intervention study aims to improve participation, inclusion, and quality of life of children with disabilities in Central Uganda. *Ubuntu bulamu* is closely related to the South African *Ubuntu* philosophy and is based on the belief in a universal bond of sharing that connects all humanity (Muwanga-Zake 2017). The *Ubuntu bulamu* intervention promotes togetherness and belonging and encourages communities to care for and include children with disabilities.

The intervention consists of a peer to peer support intervention for children with disabilities, non-disabled peers, parents, and teachers in Wakiso and Masaka districts and involves 200 families. In Phase I (2017–2019) 32 families of children with disabilities were matched with 32 families with a child in the same age group and class in the same schools and communities. In Phase I, demographic, medical, and social data of 32 children with disabilities and 32 typically developing peers and their parents were collected through interviews, focus group discussions, and photo and video voice (Bannink Mbazzi et al., 2020). In Phase II (2020–2024) another 160 families will be recruited in a randomized control design to further test the intervention. Phase II has been delayed as schools are currently closed and all regular research activities in the country were put on hold due to COVID-19.

Just after the lock-down started in March 2020 the study team received phone calls from a number of parents of Phase I of the study who were concerned about their child's health and access to health services. Some also called the study team as they were concerned their children might have an increased risk to develop more severe symptoms if they are infected with the virus due to pre-existing conditions, and asked for advice what to do if they would get symptoms.

We investigated the impact of the COVID-19 response on children with disabilities in Central Uganda during the first 5 months of the outbreak (March – July 2020).

## **Methodology**

### ***Study questions***

In this qualitative study we assessed participants' knowledge and concerns as well as the impact about COVID-19, and related public health response, on participants and their children's, and community members day to day life (health, education, economic, psychosocial), and actions participants have taken in response to the information about and public health response to reduce the spread of COVID-19.

### ***Study population***

We collected phone follow-up data from 39 parents (27 parents of children with disabilities and 12 peer parents) and 9 of their children (5 children with disabilities and 4 peer children). The children had different disabilities including hearing, visual, physical, intellectual, and neurodevelopmental disabilities and required substantial support in daily activities, a few had multiple disabilities. Approximately half of the children used verbal speech using full sentences or to communicate, whilst others used 1-2 word phrases, sounds, or sign language. Median age of the children was 9.5 (range 8 – 15), with a slightly higher number of girls participating (54.9%). All children were in nursery or primary school, with most of them in the second (33.3%) and third year (20.5%) of primary school. Most of the parent respondents were mothers (94.9%), only 2 fathers participated in the interviews. This is in line with the main study population, in which the majority of participants are mothers, followed by grandmothers, and fathers. The majority of the parents was married (64.1%), whilst 23.1% had separated, 7.7% was widowed, and 5.1% was single. The median household size was 5.2 ranging from 2 to 15 household members. The majority of parents had completed primary education (43.6%), 38.5% completed secondary education, and 17.9% tertiary education. Most parents were self-employed (38.5%), 23.1% were employed, whilst others did not have any form of employment (30.8%). All but two families had a monthly household income of less than 100 USD per month with 82.1% of them living of less than 50 USD a month.

All 64 parents and 63 children recruited in Phase I were approached to participate in the phone interviews. In total 39 out of 64 parents (27 parents of children with disabilities and 12 peer parents) accepted to be interviewed on phone, 2/64 declined, and 13/64 phones were out of reach. Of the 35 children who were staying with parents at the time of the call only 9 were able to speak on phone. It should be noted that 17 children with disabilities in the study are unable to have a verbal conversation on phone due to their disabilities. The other 14 children were not available at the time of call. The first round of interviews took place between 5<sup>th</sup> and 18<sup>th</sup> of May 2020. The second round took place between June 29<sup>th</sup> and July 17<sup>th</sup> 2020. During the second round of interviews 32 out of 39 parents (20 parents of children with disabilities, and 10 peer parents), and two of nine children (one child with a disability and one peer) of the first round were available to be interviewed on phone.

### ***Data collection***

Given the current limitation on movement and in person contact, we collected all data by phone. The phone interviews were conducted through 15

to 20 min phone calls. At the start of the call, participants were requested to verbally consent to answering questions about COVID-19 in addition to the data collection they already provided written consent for. A written note of the time, date, and the person taking the consent was recorded. We phoned participants during the period of the strict lock-down measures and the period in which the lock-down was partially lifted to understand if any changes occurred over this period of time.

During the wider study all participants had met the study team members at least five times in person. Phone contacts of all participants were on file. The phone calls were carefully introduced as a follow up on the children in the study in the light of the COVID-19 situation. To mitigate the risk of people eavesdropping or participant's being uncomfortable talking on phone with household members present, we specifically asked the participants if they would like to speak on phone in a separate room or outside to allow some privacy.

Participants were given the opportunity to ask questions in the phone call, and staff were trained on the basic medical and epidemiological information and referral procedures for COVID-19 in Uganda, using available information from the Ministry of Health and World Health Organization. In addition, staff members provided basic telephone counselling if a participant presented with anxiety or negative beliefs about themselves due to the situation. The basic counselling consisted of listening and showing empathy, providing factual information and challenging the possibly incorrect information the participant could have received about COVID-19, and replacing this with realistic information, and exploring coping strategies the participant could use to reduce the anxiety or negative beliefs they may have had. Participants who referred to other challenges such as food scarcity, and inability to reach health services were encouraged to get in touch with their community leaders to access food distributions and/or transport to medical facilities.

The phone call was recorded by the study team member conducting the interview to ease data transcription. The interview data was transcribed and analysed using thematic analysis.

### ***Ethical considerations***

There were three main ethical considerations in this study. *Expectations*: we had to be extremely careful how we presented what we were doing to avoid raising any expectations or making empty promises that could allow the participants to feel disappointed. We did this by being consistent, open and realistic about the nature of the study. *Data security*: to protect informants we did not link any data to a particular participants. We explained our procedures for keeping the information shared on the telephone secure, and



asked participants to conduct the telephone interview in a private space, where possible. *Sensitive information:* we collected some sensitive data on livelihoods during the interviews. All staff received training on managing the provision of advice and information on referral pathways where required.

Ethical clearance was sought from the UVRI Research Ethics Committee, Ghent University Ethics Committee, and LSTHM ethics committee, research clearance was obtained from the Uganda National Council for Science and Technology. For the interviews verbal informed consent was obtained from adults and assent was taken from children after their parent or guardian had given their consent. Verbal consent was formally requested over the telephone, and documented. Participants were compensated for their time in the form of mobile money (approximately 2.5 USD per interview) sent to them after the interview.

## Findings

### *Information participants received about COVID-19*

All participants reported good basic knowledge on Covid-19 prevention and measures taken and mentioned adhering to the President's directives. They reported receiving information in English and Luganda. Information was received through TV (38/48), radio (26/48), phone messages (21/48), and neighbours (8/48). All children (9/9) mentioned having received information from their parents and TV. Parents whose children had hearing impairment and intellectual disabilities described to have to either translated it in sign language or have simplified the messages when communicating to their children.

A few participants stated that they thought the Chinese made the virus, that God is punishing the developed world for not respecting him, or that African persons are immune to the virus and should be left to go to work.

"They say the virus was invented in China; they wanted to send it to Africa but I am not sure because it has killed them most" (Mother of a girl with spina bifida and hydrocephalus with cognitive difficulties)

During the second round of interviews, the majority said to have received less information in June and July compared to the first three months of the outbreak. However, most said to still worry about the continuous spread of the virus.

"We should not take this coronavirus for granted because the number of infected persons is increasing every day so if we do not take measures, most of us will be infected." (Mother of a girl with autistic spectrum disorder with accompanying intellectual impairment)

A few parents narrated that they felt the virus is just like any other disease, and emphasized the need to find a vaccination or cure.

"Corona is like other ordinary diseases such as measles, and polio which also kill the same way and which people have been living with. If possible, the scientists should struggle to invent the medicine whereby in some years to come people will be able to be vaccinated, just like polio." (Mother of a boy with an intellectual disability)

Some participants mentioned not necessarily believing that the virus is actually there and is dangerous, while others explained that due to the complacency lock-down is not lifted.

"We get the news but people believe that they are being deceived that corona actually is not there in Uganda. They got used and they are no longer as bothered as before when they used to be on tension." (Mother of a boy with Down syndrome and a speech impairment)

"Ugandans are big headed if a person hasn't yet gotten sick they can't believe that corona is actually there, so if they ease the lock-down everyone will do their own things [...] people can't follow guidelines". (Mother of a girl with cerebral palsy and an intellectual impairment)

### ***Preventive actions taken***

Participants were fearful about the disease, they described it as a disease 'that spreads very fast and kills within a very short time'. Participants mentioned good adherence to the countries' measures to ensure prevention. Regular hand washing was the most commonly mentioned measure taken, followed by avoiding crowds (social distancing), and wearing masks.

"During this time, hygiene is very important. For one to stay safe, they have to avoid going out or staying in a crowded place for a long time. Washing hands regularly and avoiding touching eyes are key." (Mother of a girl with autistic spectrum disorder with accompanying intellectual impairment)

Whilst the majority of participants reported similar adherence to prevention measures, some had become complacent or described others in their community as being complacent during the second round of interviews.

"People are just not implementing the preventive guidelines put in place and they are no longer so worried about COVID. But we stay at home and whenever I am sending the children for something, they put on masks. [...] I have water here, I bought liquid soap and the sanitizer which we put in the water. [...] [There is no one who enters the house without washing." (Mother of a boy with a hearing impairment)

### ***Effects of COVID measures on participants' lives***

Almost all (45/48) participants described the effect of COVID-19 related measures had negatively impacted them. The worst measure was considered to be the lock-down and having to stay home. Participants explained that their general health, social life, finances, children's education and health

were all affected. A few (4/48) participants reported improved relationships and understanding in their families, more social behaviours among the children, saving practices and ample time for garden work during the first round of interviews.

"This virus has been so tough but it has at least taught each one of us, rich or poor, [...] we have been with husbands who wouldn't know what we go through because they would come back in the night [...] when we stay at home, we know the daily home programs, and use resources sparingly." (Mother of a boy with spina bifida and hydrocephalus)

During the second round of interviews the majority felt the situation had worsened as lock-down was prolonged and they still had no income. All mentioned that transport costs had gone up excessively, making it difficult to move around even though the ban on movement had been lifted. A few participants had been able to return to work but most were still at home without income.

### ***Access to health care and medication***

All participants with children with disabilities reported challenges in accessing health and rehabilitation services and medication. Most of the children were taking medication regularly for their condition and would normally attend regular medical reviews at which medicine refills would also be provided. During the lock-down and ban on public transport, all those not living within walking distance from the facility were unable to attend their therapy and review appointments and access medication. Participants were greatly distressed about this as they noticed their child's health regress.

"I am worried about my daughter's health. I was supposed to go back for her results on 7th April but I could not walk to Kawaala [health facility location]. I even stopped giving her the brain pill because I can no longer afford to buy it [mother cried while talking]." (Mother of a girl with autistic spectrum disorder with accompanying intellectual impairment)

"My boy has not been able to go for his reviews and therapy exercises for over two months, he is regressing and beginning to self-injure again, we are not able to take him to the hospital as we cannot move. I cannot even carry him on my back and walk, he is very heavy and it's too far [mother cried while talking]." (Mother of a boy with muscular dystrophy with cognitive difficulties)

One of the parents mentioned she had started rationing the quantity of drugs she was giving to her child as she was not sure when the lock-down would be lifted. Participants also reported to self medicate with any medication available in the house for other symptoms that occurred during the lock-down period.

"I bought Panadol and some other medicines and that's what I give her, she [the child] gets headaches a lot and I just give her those." (Mother of a girl with an intellectual disability and visual impairment)

Some of the parents reported that the lack of medication had had bad effects, for example some children experienced frequent seizures, had issues with their bladder, became deaf, and others were said to have become very forgetful.

"He [the child] used to take drugs for his ears but since the lock-down, we are unable to go to Kisenyi [health centre location] to pick the drugs and this has affected him so much because he has almost gone deaf." (Father of a boy with a hearing impairment and learning disorder)

One of the children told us that she was well when she still had drugs to manage her bowel and bladder problems but was now leaking urine as the medication has run out.

Some of the caregivers reported poor health and were struggling to access health care services themselves. The majority of the caregivers (35/39) reported to be grateful they had not fallen sick during this period.

Access to health facilities was said to be better during the second round of interviews when movement restrictions had been lifted. However, the majority of parents reported still avoiding going to the health facility unless really necessary as transport costs are high. One parent was also concerned about attending the government facility she usually goes to as this is now a designed COVID hospital.

"What has changed is that transport is now available but accessing medical services is still hard as we have little income so I cannot go far [on public transport]" (Mother of a girl with autistic spectrum disorder and intellectual disability)

### ***Education and home learning***

All parents were encouraging their children to revise from their school books they had at home and tried to support them where they could. All struggled with home schooling and worried about their children's education. The majority mentioned that their children were unable to concentrate well on TV or radio broadcasted lessons because they are not used to that method of learning. In addition, many faced difficulties accessing the lessons on TV and radio as they frequently experienced electricity outages. Only eight out of 39 had received materials from school to continue learning at home, and four children were able to access TV and newspaper pull outs for learning. One received work sent by school through phone which they would then print out at a local shop. Parents of children with intellectual disabilities found it very hard to teach their children at home, as they did not know how best to manage behaviour and help them learn.

"She has class work at home but she cannot do it as the whole book gets filled with saliva and I cannot help her. Teachers at school tell me she is able to learn but I don't know how to make her learn [...] she cannot talk nor write." (Mother of a girl with spina bifida)

Despite the information that learning materials were sent out to local communities by the Ministry of Education and Sports, the majority had not accessed these yet, as the local councils (LC) asked them to pay around 1 euro per booklet, and they could not afford this. Most also did not have any textbooks at home to teach from.

"I don't know when this will end because we cannot afford to buy the learning materials from the LCs. We heard that learning materials from the government are supposed to be free but when we go to the LC, they tell us it is 5,000 UGX [1.5 USD]" (Mother of a girl with spina bifida)

Equally the parents were concerned about children not accessing learning through television or radios, as not all had access to this, and mentioned it was not always accessible for their child.

"I really don't know what we shall do to see schools open because that is a serious challenge [...] we don't have electricity, our children have to go to town where there is electricity and they can then learn from the TV, we have found it really challenging." (Mother of a boy with hydrocephalus and an intellectual disability)

Some parents invested in private tutoring and bought more educational materials.

"The children' schooling has been affected as well, so now we have to try and teach them from home which is not very easy [...] they get work from TV and the newspapers however the newspapers were very expensive [...] I am planning to get a tutor so that he does not regress [...] learning materials are also getting expensive because he loves to write, he goes through the books very fast and can use over 5 notebooks in a day, it's becoming a lot, I am trying to manage." (Mother of a boy with autistic spectrum disorder with severe communication difficulties)

A few parents had children in the last year of primary school, who would have normally registered for primary leaving examinations during the first school term. Parents worried that this had not happened and their children might lose out on their final school year. Others also worried about this school year being a 'dead' year and children having to repeat the year.

"I miss school so much and I don't know whether I will be promoted to primary 5" (peer to a girl with spina bifida and hydrocephalus)

"My worry is that our children are growing and they are going to repeat classes (by now they would be going for 3<sup>rd</sup> term) [...] Instead of the child going to the next class, they are going to repeat the same class and that is getting us backwards. And I am not sure if next year they will go to school! [...] they might tell us to wait for the other year or when corona is over" (Mother of a boy with autistic spectrum with communication difficulties)

Both children and parents mentioned missing school; specifically the learning, structure, and interaction with peers.

"He is tired of staying home. He always asks when the lock-down will be lifted for him to go back to school. I know he misses his friends." (Mother of a peer of a boy with an intellectual disability)

During the second round of interviews the motivation to home school and access to learning materials had drastically reduced, and the majority of parents reported that their children were instead playing most of the days.

"The challenge we have now is about schools. It's not easy because even children no longer want to revise/read. They only want to play. They get reading materials but still they don't want to do it". (Mother of a boy with spina bifida).

Parents also expressed the concern of not being able to afford school fees when school will resume due to the economic impact the measures have had on their families.

"I have nothing to do [...] I have no money at all. I can't send him back to school with this situation I am in, if I fail to get what to eat how will I afford taking him to school! (mother of a boy with autistic spectrum disorder and physical impairment)

Many parents were concerned about schools not reopening or it not being safe for the children to return to school too.

"What is worrying me is [...] classes may be overloaded [...] yet children have to be spaced [...]. We also don't know when they will open schools. We are scared since there is no social distancing at school for example in dormitories" (Mother of a peer of a girl with a hearing impairment)

### ***Economic impact***

From their narratives, all families had been affected economically since they were unable to work during the lock-down. Both the employed and self-employed were affected financially and this had compromised their quality of life/standards of living. The majority mentioned that due to financial constraints, they are unable to meet the family needs especially food as they used to. All caregivers (39/39) mentioned experiencing food shortages and rationing food, a few skipped meals.

"This situation is not working for us, things are bad, we are hungry and we have no money, it's not good times at all". (Mother of a girl with hydrocephalus)

"The major issue is food. Before this, we would move to look for food and do some work for a living but it is now impossible." (Mother of a girl with an intellectual disability)

During the second round of interviews food shortages were an even greater concern.

"There is a very big change/challenge because earlier [...] the children had breakfast, lunch, evening tea and supper but now, there is nothing. All they have is only one meal a day". (Mother of a boy with an intellectual disability)

"What I do now is that I prepare maize porridge for my children at around 11am and they keep playing until 3pm or 4pm then we have lunch. When I serve lunch at this time, I am sure they will not ask me for supper." (Mother of a girl with hydrocephalus and cognitive difficulties)

At the time of the first phone calls 5/39 families had received food distributions from the government, whilst 13/39 had received food from a parents support group. Others suggested that government could distribute food through the local leaders and give priority to families with children with disabilities. In the second round of interviews none of the parents had received food distributions.

"Right now, access to food is the biggest problem. Some of us used to earn daily for daily food and because of the lock-down, we can't and we are not sure when this will end. I would suggest that the government sends to communities enough food before our children die." (Mother of a girl child with Down syndrome)

The food shortage did not only affect the families' nutritional status but also their health and relationships. Some mothers said that their blood pressure had gone up and others said they just find themselves too harsh to everyone because they are overwhelmed and cannot meet the family demands. One of the parents mentioned not giving her son the medicine he is supposed to take as he needs to take these with food. Another mentioned beating her child because she never used to eat posho (a local dish made of maize flour) and now had to force her to eat it as there was no alternative food at home.

Those that were still employed (9/39) all were worried they might lose their jobs. Those who have small businesses said their income is very low. They can no longer move to big markets to purchase goods, and worry about the future as they have used up almost all the capital they had.

"Business is not going well, I am not able to buy stock for the shop because of transport and town being closed, so now we have eaten everything in the shop that can be eaten and gone down to the capital and profit as well." (Mother of a boy with autistic spectrum disorder)

The few (5/39) that had access to land were happy they can at least grow some food from their gardens.

"We have not had very tough times in terms of food. We have been having some food in the garden and we are in the garden now planting cassava" (Mother of a boy with hydrocephalus)

During the second round of interviews participants raised concerns about increased transport costs, having to pay rent, and the continued lock-down which was affecting their income.

"At first I was worried about how I will handle my children but now I am worried about food and rent for the house because the landlords also need their money" (Mother of a girl with autistic spectrum disorder with intellectual impairment)

"We are trying to survive [...] people are broke yet they have families to care for. They should remove the lock-down so that people can go back and work" (mother of a girl with cerebral palsy with communication difficulties and intellectual impairment)

### ***Psychosocial effects***

Participants reported experiencing a lot of emotional distress due to the financial difficulties as well as home schooling. Some of them reported sleepless nights, loss of appetite and anger due to stress related to lack of food and finances. They also noticed their children are distressed.

"Children are crying saying the situation is difficult. They are unhappy because they see us sad." (Father of a boy with a hearing impairment and learning disorder)

Socially parents were used to meeting and working as a group as a way of supporting each other and they would also get support from friends or families. This has all stopped as each one is thinking about their own children which has increased stress levels.

"I have not met with anyone so far. I just stay home and even getting airtime now is hard. The money you think of buying airtime you at least buy pancakes for the children or water or charcoal so I have really not so much communicated and consulted with them." (Mother of a boy with an intellectual disability)

Some parents also reported the difficulties in not being able to attend funerals.

Children also mentioned about not being happy because they miss their friends and they are unable to play as they used to at school and in the neighbourhood.

"I miss my friend. I used to do work with her but I am now doing it alone. I miss her very much." (peer to a girl with spina bifida and hydrocephalus)

Some however mentioned to play and attempt to socially distance at the same time. They had different opinions on what was safe play in relation to COVID-19 prevention.

"We play football but this one is made out of banana fibres and we play carefully. We don't get close to one another." (boy with hydrocephalus)

"We play *ludo* (a board game) [...] not football [...] when you kick the ball to the other person, COVID goes with it." (peer to a boy with a hearing impairment)

A few parents were concerned about their children's behaviour and the risks they may be exposed to now they were home without structured education for too long.



"We are home but we can't control the boy, he is away with friends and getting some money. We cannot keep him at home anymore. [...] He is getting out of hand and it is like he is running mad, he can't settle and we need help to manage him" (Mother of a boy with an intellectual disability)

"Why don't they allow school heads to open their schools and they give them guidelines to follow at school because what we have faced at home is children are getting pregnant because you tell children to stay at home and you find they have left home to go somewhere else and you are not there to monitor them all the time. We are the parents but we can't protect them as much as they do at school." (Mother of a girl with spina bifida and hydrocephalus)

### ***Follow-up phone calls as part of *Obuntu bulamu****

The intervention of the larger research study *Obuntu bulamu* promotes togetherness and belonging through a peer to peer support approach. Participants appreciated receiving a phone call from the study team, they said the call encouraged them, and were happy the study team had 'remembered' them in these difficult times. One of the participants mentioned that due to COVID-19 people no longer call.

"Everyone is minding their own business now. You only call when you must. No more business of chatting because we can't afford airtime" (Mother of a girl with Down syndrome)

They were pleasantly surprised that the team could call them and talk to them. A participant expressed gratitude for being checked on and put her son who has an intellectual disability and is unable to verbally communicate on the phone, he made sounds in response to the interviewers' voice.

In total 47 out of the 48 participants responded very positively to the call. One person presented neutral. There were no negative reactions to the phone calls. Participants did expect guidance and sometimes financial support from the study team.

"I have been going through a lot. I have been asking myself where you disappeared. I even had got annoyed but I am happy now. Thank you for checking on us." (Mother of a boy with Autistic Spectrum Disorder with accompanying intellectual impairment)

In total all but one caregiver reported they had received social support through their parent support group. Parents had shared information about how to take care of children with disabilities whilst in lock-down on phone. Others had just called each other to check in on each other, and comfort each other. Some had had questions about access to treatment. A few received medical supplies from the parent's leaders and 13 caregivers reported to have received food from their support group.

## Discussion

The non-pharmacological COVID-19 response has had a marked impact on the health, education, economic and psychosocial situation of children with disabilities and their families. Whilst some concerns are shared with others globally, the families reported specifically having difficulties in meeting daily basic needs, in accessing health care for chronic conditions, and engaging in meaningful home education and learning.

Overall caregivers in our study were well informed about COVID-19 and related measures. Not all communication was accessible and age appropriate, but caregivers would ensure to communicate the information to their children (with disabilities) in their own way. The Stakeholder Group of Persons with Disabilities (2020) earlier found that masks and hand sanitizers which were promoted as a preventative method against contracting COVID-19, were often not widely available and/or unaffordable. They also reported that face masks caused frustration in persons with hearing impairments. In our study, participants did not report this challenge, perhaps because very few people are actually seen to wear masks on the streets in Uganda, hence they may not have felt these were missing or barriers to communication. They did not report difficulties in having access to basic water and soap for hand washing, as reported in other African countries (Kivuti-Bitok et al. 2020; Shigute et al. 2020). They did however report some complacency four to five months into the outbreak.

Access to health care services and medication was a major issue raised by our study participants. This causes concern for management of their chronic conditions and the long term impact the absence of health and rehabilitative services may have on their development. It also increases their risks for COVID-19 as they are physically less fit and healthy than they were earlier when they had access to health services. In the Stakeholder Group of Persons with Disabilities (2020) report, mention is made of the lack of accessible transportation during the pandemic, and access to drugs, health and rehabilitation services in African countries due to the restrictions on movement. This, the authors say, has resulted in persons having deteriorating health conditions, and regression in persons who relied on regular occupational, physio and speech therapy. Participants in our study did not only raise concerns about accessing disability specific services, but also worried about access to medication for other chronic illness such as HIV. Various authors have earlier emphasized the importance to not lose valuable progress that has been made regarding the fight against various infectious diseases (e.g. HIV, measles, meningitis, and tuberculosis) whilst addressing COVID-19 in low income countries (Gupta et al. 2020; Kimani et al. 2020; Mensah et al. 2020; Roberts 2020).

In addition, a main concern raised was the issue of lack of income and therefore food. Most of our participants run small businesses and are dependent on daily sales and income. The Stakeholder Group of Persons with Disabilities (2020) report also mentioned the dependence on day labour to put food on the table, and the challenge the lock-downs have posed to make ends meet, despite the food that was offered. They argue that as it was not possible to continue this daily work for many, COVID-19 is not a threat as a disease, but one of survival. Ataguba (2020) confirms and draws a rather grim scenario of the African economies post COVID (Ataguba 2020). In our study we found participants had similar experiences, especially as the number of cases in Uganda is low and only a few deaths were recorded at the time of this study, participants were very concerned that they instead suffer from food insecurity and other diseases for which they may not be able to access health care. Whilst some had benefitted from the government distributed food during the first three months of the outbreak, most relied on hand outs from neighbours and members of the parent support group they are part of through our intervention. Despite the release of some of the lock-down measures most participants narrated a deteriorating situation in the later months of the outbreak. The effects of possible prolonged lack of food for many of the families could have serious health and developmental effects over time especially for children. In Nigeria, Kalu (2020) has raised concerns about the detrimental effect the COVID-19 measures could have on the progress made in treating and preventing malnutrition in sub-Saharan Africa. Earlier Renzaho (2020) argued to tailor responses to demographics, disease burden, economic situation, health sector status and cultural beliefs and customs (Renzaho 2020).

The social and psychological effects of the COVID-19 measures have been widely described in high and middle income countries (Anderson et al. 2020; Dong et al. 2020; Liu et al. 2020; McKibbin and Fernando 2020). Other studies have shown high anxiety around the virus and possible illness and death of the same (Gao et al. 2020; Nicomedes and Avila 2020). Very little is still known about these effects in sub-Saharan Africa. The Stakeholder Group of Persons with Disabilities (2020) report mentions increased anxiety in persons with intellectual disabilities about their lives being at risk. Whilst some anxiety was expressed in our study population, most participants raised concerns around the impact of the measures rather than a fear of the virus itself. This difference could possibly be explained by the relative low number of cases of COVID-19 infections and deaths in Uganda, as well as participants' exposure to and having learned to cope with various other life threatening situations in the past. In our study we found the virus has impacted social gatherings and support.

Whilst participants felt happy to receive a phone call, they also expressed missing social interactions and gatherings. Earlier Manderson and Levine

(2020, p.369) described how the social urge to gather, celebrate, and worship together is under threat. They explained the virus asks for counter-intuitive action for 'self-protection and protection *'not only for self-protection but more so for the protection of those whose immune systems and social support systems are compromised by inequality'* (Manderson and Levine 2020).

Home schooling was one of the most challenging aspects mentioned by our participants. Internationally others have raised concerns about home schooling children with disabilities (Cluver et al. 2020; Toseeb et al. 2020). Given the challenges children with disabilities already face in inclusion and learning school, this raises concerns of leaving them behind even more.

Missing out on school also results in a change in social contacts. In our study we noticed children missed their friends from school. However some explained to play with children from the neighbourhood. Child protection concerns due to extended home stay and possibly lack of supervision has been mentioned as a risk of home schooling (Cluver et al. 2020). Some of our study participants raised similar concerns, especially around teenage pregnancies.

The study was limited to a small group of parents and children with disabilities living in Central Uganda and the method of phone data collection. Phone interviews have various challenges, including response bias of the respondent, as they may be in a space where other people can overhear their conversation. It also leaves out those who are not available on phone due to the absence of a phone or access to electricity; these participants might be even more vulnerable. During our interviews we also often had the phones 'go off' due to network difficulties or the participant's battery running out. Interviews were hence interrupted and restarted several times which could have led to loss of information. Similarly the recordings of the interviews are susceptible to noise which could have affected the quality of the data transcribed. However the phone interviews were a great way to collect data in this time of COVID-19 as it reduces the chances of transmission and allows researchers to still collect data from study participants. Our participants were pleased we phoned them, as they felt part of the ongoing study and were keen to share their experiences about COVID-19 with the study team.

In conclusion, we suggest greater attention to children with disabilities and their families when implementing mitigating and long term responses, and make the response country specific. The WHO policy brief on disability inclusion (2020) as well as the Stakeholder Group of Persons with Disabilities (2020) recommend to include persons with disabilities in COVID-19 response efforts, advocate for accessibility, and develop a disability inclusion guide based on lessons learned from the pandemic for governments and local authorities. Children with disabilities and their families should be considered when developing and communicating responses to the COVID-19 outbreak. They should be considered

when health and rehabilitation responses are developed and should be a priority group for care. Equally educational and home learning approaches need to take into consideration the absence of learning support staff at home, and develop creative support through phone calls, and where possible parental, peer or sibling support in the home instead.

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The authors have no competing interests to declare.

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## ORCID

Femke Bannink Mbazzi  <http://orcid.org/0000-0001-6436-3431>

Janet Seeley  <http://orcid.org/0000-0002-0583-5272>

## Data availability statement

Data are archived at the MRC/UVRI & LSHTM Uganda Research Unit and may be accessed on request to the corresponding author.

## Disclaimer

The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the funders.

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